

5. Teaching Advocacy with Patients and Families

Teaching Advocacy with Patients and Families

One important aim of medical education is to convey the knowledge and skills needed to advocate for patients and families in complex healthcare systems. When teaching about advocacy, patient- and family-advisors who live with complicated or long-term health conditions bring knowledge about needed resources and appreciation for a physician's role in linking patients and families with these resources. Teaching about advocacy may begin with an encounter with a standardized patient who presents a complex medical and social situation. In such an encounter, the learner's task is not to do a medical assessment, but to build an understanding of the goals and wishes of the patient and discuss healthcare and community resources that can help the patient achieve those goals. This may be followed by small group discussions with parent- or patient-advisors that have experience with a serious medical challenge such as a stroke, an organ transplant, or cancer. The advisors work intensively with a small group of learners to complete activities that emphasize ways to plan collaboratively for good care within the context of a patient's life and goals.

Goals

- To expand communication skills for listening to, eliciting conversation with, and building an understanding of the perspectives and priorities of patients and families.
- To equip medical students or residents with an overview of available healthcare and community resources as well as information about how to link patients and families with these resources.
- To build an understanding of how these resources facilitate patients' goals for "doing well" with their medical conditions.
- To convey attitudes needed to build alliances with patients and families.

"Talking to the students is so valuable. The one-on-one is so important ... I feel it's my role to help educate. Whether the students go into military medicine or civilian practice, they will work with families."

—a parent-advisor

Objectives

Medical students or residents will:

- Describe the components of a broad definition of what it means for patients to do well, to include patients' overall well-being and functioning in home and community environments.

- Apply the communication skills needed to conduct a patient interview that elicits the following:
 - A patient's and/or family member's definition of what "doing well" with their medical condition means to them.
 - The priorities and needs of a patient and family.
 - The context of a patient's life.
- Write a patient-centered description of a patient's and family's needs as described by the patient and/or family.
- Describe broad categories of services available to patients and families and the physician's role in linking them with needed services that meet their priorities and needs.
- Write a list of the healthcare and community resources that match a particular patient and family's priorities and needs.

Curricular Context

"Each family is different and doctors need to not always go with 'the norm' but treat each family uniquely. Each family goes through things differently. Just because the book says that the family ought to be responding in one way doesn't mean that this is the case."

—a parent-advisor

At the Uniformed Services University, a coordinated set of activities in the Family Medicine Clerkship is used to teach medical students about advocating for patients and families. Students participate in a three-hour workshop, do a home visit followed by a written assignment that emphasizes resources for patients and families, and complete a standardized patient encounter. The workshop could easily be adapted for any clinical clerkship, for an intercession or another setting for teaching topics that cross disciplines, or for a residency program. We sought to address the ACGME competency for residents that states, "residents will advocate for patients in complex healthcare systems,"¹ and we developed this workshop to build a foundation for this competency among medical students.

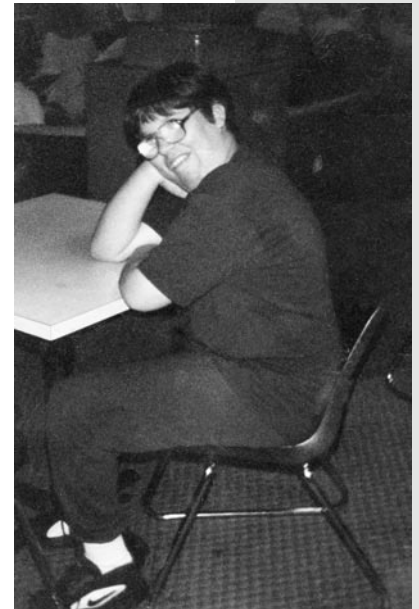
Description of the Activity

In a series of interviews and focus groups, people with chronic health conditions developed the definition of advocacy that appears in the box below. They were emphatic about the importance of a physician building a relationship with a patient and family and developing a thorough understanding of their circumstances, priorities, values, and daily activi-

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ties before recommending services or trying to connect them with resources. Therefore, this activity centers on opportunities for learners to talk with patient- or family-advisors in small groups to build an in-depth understanding of a person with an ongoing or complex health condition. Essentially, learners come to understand the three parts of this definition of advocacy as they interact with patient- or family-advisors who share their stories in detail over the course of a three-hour workshop.

Since this workshop teaches about planning medical care in the context of people's lives and about integrating healthcare and other community resources, it is best taught by a team that includes both a physician and a medical educator with a background in social work, education, communication, psychology, or a closely-related field. The physician brings experience in making medical decisions with patients and linking them with the services they need. A professional with a background in a social or psychological field brings experience with a wide array of formal and informal community resources and an in-depth understanding of the complexities of living in homes and communities with a chronic or complicated health condition. The session works best with a skillful facilitator who will succinctly explain important information, engage the large group in short discussions and then set up small group conversations, leaving ample time for the patient-advisors to engage actively with the learners, explaining their lives and perspectives in detail. The small groups work well with one patient- or family advisor for each group of five to seven learners.



Advocacy: A Working Definition

- Build a relationship with each patient in order to understand what the patient needs. Learn what “doing well” with the medical condition means to each patient.
- Care about each patient and about his or her family; help them achieve their goals; think about the whole patient, not just the disease, and plan medical care with the whole patient in mind.
- Take the initiative with the resources at hand to help each patient and family achieve what is medically and personally important to them.

Outline for the Advocacy Teaching with Patient- and Family-Advisors

Introduction (20 minutes)

1. Introduce the patient-generated definition of advocacy.
2. Discuss the story “Between Yes and No.”
3. Elicit the learner’s goals.
4. Share illustrative examples of physicians advocating for patients and families.

Exercise on “doing well” (20 minutes)

Small Group #1: Discuss priorities with patient-advisors (20 minutes)

Review approaches to communication (30 minutes)

1. Introduce PEARLS for communication.
2. View a video on communication (*Rowing Upstream, Downstream*).

Small group #2: Discuss the context of their lives with patient-advisors (20 minutes)

Break (10 minutes)

Overview of healthcare and community resources (30 minutes)

1. Introduce and discuss a notebook or compact disc (CD) about resources.
2. Explain care coordination, case management, and social work.

Small group #3: Discuss resources with patient-advisors (20 minutes)

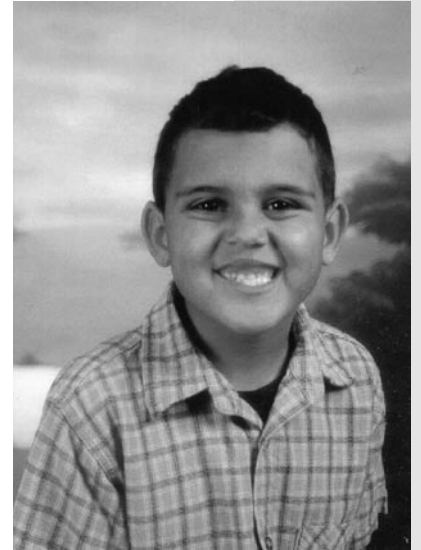
1. What resources are important to this patient and family?
2. How to link patients and families with the resources they need.

Summary and closing (10 minutes)

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Introduction to Advocacy (20 minutes)

The three-hour workshop begins with an introduction of the patient- or family-advisors, who are seated from the beginning of the session with small groups of learners, one advisor with each group. Introductions are followed by an explanation of the definition of advocacy and its origins in interviews and focus groups with patients who have chronic or complex health conditions, then by a discussion of a story written by a patient about an experience with a physician who advocated in a way that made a difference. Several such stories appear in the “Patient Experiences” section of the website for the American Academy on Communication in Healthcare (AACH); the one we use is entitled, “Between Yes and No.”² The story sets the stage for a discussion about how the physician in this narrative illustrates building a relationship, understanding a patient’s goals, and taking the initiative to make a difference for this patient.



This description of advocacy and the AACH story create a setting that serves as an opportunity for learners to reflect on their own readiness to advocate for patients and families in this way. What knowledge and abilities can they identify that will help them advocate effectively for patients and families? What would they like to learn to help them become more effective in understanding their patients, building relationships, planning care collaboratively, and linking them with healthcare and community resources? The workshop may include a discussion of learners’ goals, generation of a list of group goals on a flip chart, or time for learners to write individual goals.

Although the most obvious setting for advocacy for individual patients and families is discharge planning, advocacy occurs throughout the continuum of care—in an acute care setting or in a hospital. Advocacy means planning health care in the context of people’s lives in their homes and communities. Sometimes it requires extra time and effort; sometimes it simply requires the time and effort to listen to the patient and shift priorities to match what is important to that person in the context of his or her life. In this case, an illustrative story from a physician, such as the one below, provides clarification and inspiration.

“I was at my comfort point in my relationship with my new patient, a retired physician-general officer, to discuss his thoughts regarding advanced directives, life values, and end-of-life care. Over a series of visits, I learned about his personal health problems (thankfully few), and a lot about his long and distinguished career as a military physician. What impressed me the most in my conversations with him through those initial conversations was his undying devotion to his wife, who was a total-care patient at the premier nursing home in our community.

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She followed him dutifully through his career, and their well-deserved retirement together was cut short by a devastating stroke that left her an invalid.

I knew what his answer would be when I asked for his opinions about CPR and code status. How could any 85-year-old physician want to go through the futility of a code? I was floored when he responded that he wanted ‘everything’ done to keep him alive, and to cease care only upon brain death. Dumbfounded, I asked why.

‘Because as long as I’m alive my retirement pay continues, and my wife will get the best possible care available,’ was his response. I felt like an idiot, and cursed the assumption I had made. I never thought that wanting to go through a code and aggressive end-of-life care would be an act of love. Now I know better. Having listened to this distinguished gentleman who was my patient, I knew how to advocate for him, and to support what was of ultimate importance to him.”

-COL Brian K. Unwin, physician

Assistant Professor of Family Medicine

Exercise on “Doing Well” (20 minutes)

We learned about the concept of “doing well” from the same group of patient-advisors who wrote the definition of advocacy in response to the question, “What does it mean to do well with your health condition?” Their answers taught us that doing well means: “tying my shoes by myself,” “cooking dinner for my children,” “getting back on the golf course,” or “keeping my job so I can support my family.” In the workshop, the following exercise helps learners reflect about what would most concern them if they unexpectedly found themselves with serious health needs.

Exercise for Pairs of Learners

Ask the learners to each find a partner to discuss what “doing well” would mean to them if they encountered an unexpected, major medical event in their own lives, such as being in a serious car accident. Ask each partner to talk for two or three minutes about what worries would be foremost on their minds if they woke up in the ICU after a major accident or sudden onset of a very serious illness.



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Summarize in Large Group

In the large group, ask the learners to share what worries and concerns they discussed. Write their comments on a flip chart, separated into these three categories:

- Values.
- Activities of Daily Living (ADLs and basic life functions).
- Instrumental activities of daily living (IADLs, activities in which a person applies ADLs to a role such as a job or a complex task such as managing money).

Summarize the themes with the large group, noting that people often have a drive to return to their life as they knew it before the medical event intervened and fear that this will not be possible. A medical event usually creates altered circumstances that may change the way people live their lives, either temporarily or permanently. Part of a physician's job includes figuring out how to support people in living their lives under these altered circumstances.

A man in his 40's with a prosthetic heart valve went out for a run on a Saturday morning and woke up the next day in the ICU, having had a stroke. He awoke determined to finish preparing the grades for his high school math students, as the grades were due on Monday morning. His drive to finish the grades exemplified his desire to return to his roles as teacher, provider for his family, father and husband. When his wife's protests did not lessen his determination, she called their 17-year-old daughter, who gathered his grade book from the family room floor, brought it to the hospital, and completed the required record sheet of grades while he watched and then dictated comments about his students. Once these priorities were addressed, he was ready to discuss the stroke, necessary medical tests, and next steps in the hospital.

Introduce the PASS-C Form

While the exercise about "doing well" helps learners understand how the context of a patient's life relates to health conditions, they may not know what questions to ask in order to learn about a particular patient. A form called the PASS-C (Priorities, Activities, Social and Family Context, Support and Coping—Coordination) structures the balance of the workshop around discussions with patient- and family-advisors in small groups. In the first small group session, the learners discuss the priorities and values of the advisor in their

"[Technological tools] will never replace the patient-physician relationship. They won't ever replace the ability to go in and talk with your patients."

—Thomas DeGraba, M.D.

group, the health condition of the advisor or a member of his or her family, and the life activities that are affected by the health condition. In the second small group session, they discuss the context of that person's life, including the social and family context in which they live and the sources of their support. In the third small group session, they discuss the wide array of healthcare and community resources the person has needed and ways that physicians can link people with those resources. The form appears in the Appendix.

Small Group #1: Discuss Priorities with Patient-Advisors (20 minutes)

The learners get acquainted with the advisor in their group, discovering which family member has a chronic or complex health condition and what “doing well” means for this patient and family in light of the medical circumstances that they have encountered. What are the goals, priorities, and values of this person and his or her family? Learners begin to complete these three sections on the PASS-C form: Priorities, Activities and Social and Family Context. After the discussion, a learner from each group summarizes the priorities this advisor described for the large group.

Review Approaches to Communication (30 minutes) ***Communicating to Build Relationships***

Depending on the level of education of the learners, there are varying needs for review or development of communication skills. It may be helpful to ask them to remember their course about the medical interview and review the characteristics of good questions, or to discuss the types of statements that promote good relationships with patients and families and offer helpful responses to emotions. One set of statements that help develop a relationship of trust with a patient and family are the PEARLS³, which appear on the next page. Some groups may appreciate a videotape that illustrates good physician/patient communication, such as *Rowing Upstream, Downstream: The Patient's Narrative* from the University of Colorado Medical School, a videotape that also serves to lighten the mood with humor.⁴



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PEARLS³

PARTNERSHIP

"Let's tackle this together."

EMPATHY

"That sounds hard."

"You look pretty upset."

"You seem discouraged."

APOLOGY

"I'm sorry I (or others) hurt you."

"I'm sorry you are ill."

RESPECT

"I appreciate your (courage, decision, action)."

"You have really worked hard on this."

LEGITIMIZATION

"Anyone would be (confused, sad, irritated) by this situation."

SUPPORT

"I'll stick with you as long as necessary."

Small Group #2: Discuss the Context of their Lives with Patient-Advisors (20 minutes)

In small groups, with one patient-advisor in each group, the learners explore the context of the life of the patient/family member in their group. What is the story of this patient-advisor and family? What details about their life would be important when planning care and services? During the discussion, they fill in Activities, Social and Family Context, Support and Coping, and Coordination and Payment on the PASS-C form. They also consider how what they have learned about the advisor in their group and his or her family would affect decisions a physician might make when planning care for a patient.



***Overview of Healthcare and Community Resources and
The Role of Social Workers and Care Coordinators (30 minutes)***

In the context of advocacy as it has been developed here, healthcare and community resources provide the key that helps people live their lives, address their priorities, and live well with their health conditions. A large group discussion introduces a notebook or compact disc (CD) that provides an overview of resources with a sample booklet about the benefits in a healthcare plan, and helps acquaint learners with the wide array of care and services that people may need. The categories of services surveyed in our healthcare and community resources CD appear in the Appendix. An explanation of the varied but overlapping roles of case managers, social workers, and care coordinators is also helpful.

Small Group #3: Discuss Resources with Patient-Advisors (20 minutes)

In small groups, the learners ask each patient- or family-advisor to explain the resources that they have needed, how they found these resources, what role a physician played or could have played in connecting them to these resources, and what difference each resource made to them. The goals are to supply the students with a fairly long list of resources, to give an overview of how much effort it might take to get the needed resources, and to make it clear how a physician might help a patient and family with this process. The learners complete the sections for resources on the PASS-C form using their patient- or family-advisor's situation as a case study. Someone from each small group then describes what they have learned to the large group.

Questions for a Small Group Discussion about Resources:

What resources have you and your family needed?

What role has a physician played in helping you find or get connected with those resources?

Summary and Closing (10 minutes)

At the close of the workshop, we elicit reflections from the patient- and family-advisors. We ask them, "What is it like to have these students or residents ask questions, listen to you, and try to build an understanding of your life and the care that you or the person you love needs?" They respond with motivating statements like this recent comment from the mother of five children, four with special needs: "When the students ask these questions and listen when I talk about my family, it helps me believe that someone cares."

"If equal parts of compassion and common sense aren't part of medicine, no amount of science and technology will make it work."

Evaluation of Student or Resident Learning

We have evaluated medical students' learning about advocacy in two ways: with an advocacy case as part of an end-of-clerkship OSCE (Objective Structured Clinical Examination) and with the students' written reports of a home visit that follows the workshop. After the home visit, they complete the PASS-C form for the patient/family they visited and write a summary paragraph that describes the goals, priorities, and values of this patient and family, the context of the patient's life, the resources this patient and family need to live life well with their health condition, and the role that they would fill as a physician to advocate for this patient and family. Some sample responses of medical students to this assignment appear in the Appendix.

The Role of Patient- and Family-Advisors

Patient- and family-advisors provide the heart of both the cognitive content and the emotion of this teaching. About half of the three-hour timeframe is spent in small groups with them, discussing in detail their personal experiences with health and disease in life context, and the difference it makes to encounter committed physicians who have advocated for them. Much of the remaining time is shaped by discussion of their situations and insights. Participating in this rather intense set of discussions requires some preparation, which is summarized on a handout that appears in the Appendix. Before participating in this teaching session for the first time, patient- and family-advisors usually have one or two conversations with a faculty member or a veteran participant, using this handout as a guide. Despite the intensity, they find this activity important and energizing, as they believe it will influence the learners who participate in such a way that they will make a difference as physicians in the future.

"This has nothing to do with being 'touchy-feely.' It has to do with whether you can communicate and listen effectively. You need the ability to work with the patient and the science to promote health. You have to have all three things—listening effectively, working with the patient, and knowing the science. Superiority in one area can't make up for deficiency in another."

—Kathy Vestermarck,
parent- and patient-advisor

References

1. Accreditation Council for Graduate Medical Education. ACGME Outcome Project. 1999, Revised in 2005. Available at <http://www.acgme.org/outcome/comp/compFull.asp>. Accessed January 31, 2006.
2. McCollum S. *Between Yes and No*. Available from the American Academy on Communication in Healthcare at <http://www.aachonline.org/membership/patientexperiences/betweenyesandno.htm>. Accessed June 7, 2006.
3. Clark W, Hewson M, Fry M, Shorey J. Communication Skills Reference Folder American Academy on Communication in Healthcare, St Louis MO. 1998
4. *Rowing Upstream, Downstream: The Patient's Narrative*, a film directed by F. W. Platt, M.D. at the University of Colorado School of Medicine. Used in the Foundations of Doctoring Curriculum. 2001.

"People go into medicine to help people. It doesn't always have to be with the ... miracle surgery, it can sometimes be with the miracle of helping people live their lives better. We just need to remind them of the skills that they have. That it's not all technical and it's not all scientific, but that it is person-to-person communication."

—William Sykora, M.D., faculty